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UNDERSTANDING PATIENT AND RELATIVE/CARER EXPERIENCE OF HIP FRACTURE IN ACUTE CARE: A QUALITATIVE STUDY PROTOCOL

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ABSTRACT

Background: This paper presents a qualitative study protocol focusing on older peoples' experience of recovery in acute care following hip fracture and also the experiences of their family or informal carers. There is limited evidence regarding older people and their relatives/carers experience of recovery in acute care.

Aim: The study had two research questions. First what is the experience of older people who have suffered a fractured hip and secondly what is the relative's/carer's experience of being alongside a person who has suffered a fractured hip?

Methods: The methodology chosen is phenomenology using the methods of interviewing and participant observation. It is planned to recruit a purposive sample of: up to 40 patients including those with memory loss who have suffered a fractured hip; and up to 30 of their relative/carers; and up to 20 staff may choose to take part in the observation sessions. Analysis will be through drawing out units of meaning, bringing them together to form categories and themes of experience.

Conclusion: This study will extend knowledge by exploring what is important to patients and their relatives/carers in the early phase of recovery. Practice based principles that can be integrated into the hip fracture pathway and enhance future care will be developed from the study findings.

Key words: Nursing; Hip Fractures; Frail older people; Acute care; Qualitative research; Memory loss; Life changing events; Carers; Phenomenology

INTRODUCTION

This paper presents a qualitative study protocol focusing on recovery from hip fracture in older people whilst in acute care. A study protocol provides a guide to ensure transparency, standardisation of study procedures and trustworthiness of the findings. Publication of a protocol may in addition provide an opportunity for debate and improvements in the design of future studies. Understanding older people's experience of recovery and their family/carer's experience of supporting them is essential to provide an evidence base for practice. Current evidence suggests that patients struggle to manage on a functional, emotional and practical level (Brett, 2014). Family and carers who engage in care also work hard to juggle their lives and provide the emotional and practical support required (Nahm et al., 2010). A range of studies provide insights into aspects of the experience, but there is limited evidence about the early phase of recovery during hospitalisation and a lack of inclusion of people with memory loss. This study aims to address this gap in the evidence base. The findings will help to strengthen the person and family centred approach to acute care for people with hip fracture.

BACKGROUND

Hip fracture is a common cause of death and disability, mainly affecting older people. According to the British Orthopaedic Association (BOA, 2007), approximately 300,000 patients with hip fracture occur annually and projections indicate that the number will double by 2050. The National Hip Fracture Database (NHFD, 2014) reports the average age of a person with hip fracture as 84 years for men and 83 for women, 72.3 % of fractures occur in women but men had more comorbid conditions and higher mortality rates (Arinzon et al., 2010; Dudkiewicz et al., 2011; Endo et al., 2005; Geusens & Dinant, 2007; Samuelsson et al., 2009; Sterling, 2011).

To support the development of this protocol a review of existing literature drew on a comprehensive analysis of the experience of hip fracture undertaken by (Brett, 2014). In addition a systematic review of carer's experience of supporting a family member/friend who has suffered a hip fracture was undertaken (Disability and Rehabilitation, under review). These sources of evidence provided an insight into areas that required further exploration through research in order to strengthen the evidence base in this area. A brief summary of key elements of the literature related to patient and relative/carer experience are presented.

The experiences of patients and their families are a key component in the provision of high quality, patient and family centred compassionate healthcare (D.H, 2008). Research evidence on patient experience of hip fracture demonstrates that recovery from a hip fracture is a complex and traumatic experience. It highlights how patients make sense of their injury and the impact it has on their daily lives (Archibald, 2003; Olsson, 2007; Sale et al., 2012; Santy & Mackintosh, 2001; Schiller et al., 2015). Studies do not tend to include people with memory loss (Mundi et al., 2014) despite an estimated prevalence of approximately 40% (Seitz et al., 2011). This creates a gap in the evidence base for the experience of hip fracture but also means that a large proportion of the group remain unheard. The value of this study is that people with memory loss are included in the sample.

Building on Bury's concept of biographical disruption (Bury, 1982) or Meleis's notion of transitional experience (Meleis et al., 2000), researchers have widely explored how individuals face, negotiate and explain their physical symptoms in a wide range of illness (Hurd Clark & Korotchenko, 2011). In this study the participants are in the first phase of transition from being well to being injured and are in the process of making sense of their injury. Studies have found that older people tend to attribute their symptoms and the resultant consequences of illness to normal and age-related changes in order to normalize their experiences (Hurd Clark & Korotchenko, 2011). However evidence in the experience of a fractured hip is limited and older people make sense of their injury in different ways. Some patients explain their fracture as an unavoidable accident or chance event not related to a disease or their old age (Huang et al., 2014; Sale et al., 2012). In contrast other patients experience their hip fracture as a sign of ageing and forthcoming death (Ziden et al., 2008).

Recovery from hip fracture is difficult to define (Olsson, 2007) and is often complicated by comorbidities. There is a loss of independence and increasing dependence on others (Archibald, 2003; Huang et al., 2014; Olsson, 2007; Schiller et al., 2015; Ziden et al., 2008). For example, restricted daily life made patients feel dependent on others; they were worried about permanent dependency and felt insecure about recovery and their future (Ziden et al., 2008). The evidence suggests that the experience of a fractured hip has major consequences for older people's recovery, how they live and their relationships with others (Huang et al., 2014; Ziden et al., 2008). However the nature of this evidence is variable in terms of the methodology used, samples are often small and theoretical and analytical processes not identified. In addition little is known about the early phase of recovery whilst in acute care. This study will therefore focus on patients' experience of a fractured hip in acute care. This may include their perception of the quality of care they received and their experience of receiving surgery but the focus is the patient, their experience of hip fracture and what is important to them. It will draw on individual, contextual and social factors of ageing to provide a deeper understanding of the impact of injury on the older person.

The recovery phase after a hip fracture is often difficult for older adults, and the role of informal caregivers is particularly important (Macleod, 2005) for example, sharing information about the patient with healthcare professionals (Nahm et al., 2010). Frequently the unexpected role and the number of activities that occurred felt overwhelming. Stress, anxiety, frustration, sadness, confusion and lack of time to balance the new role with their personal-life were common feelings identified by carers (Giosa et al., 2014; Nahm et al., 2010; Toscan et al., 2011). Moreover, carers often described the hospital setting and procedures as uninviting and expressed their discontent with the lack of information they received (Giosa et al., 2014). Furthermore, it is well known that the physical, psychosocial and economic impact of caring for family members is higher in women who, due to their gendered roles, continue bearing the overwhelming responsibility for home and long term provision of care services (Navaie-Valiser, 2002; Paoletti, 2002; Pinguart & Sorensen, 2006; Twigg et al., 2011). Some studies identified that carer's burden and needs change during different phases of recovery (Giosa et al., 2014). The burden was greatest after surgery and decreased over time with a satisfactory recovery and when carers had a better knowledge about their own role (Giosa et al., 2014; Nahm et al., 2010). In this study carer burden may be an issue as family/carers move towards a more active/supportive role as a result of the hip fracture. This evidence highlights the need to include relatives/carers in research and understand how traumatic injury impacts on their lives and examine what is important to them during the acute phase of injury. Extending knowledge of what is

important to relatives/carers taking into account gender, ageing and memory loss will provide a basis for improving person and family centred care.

In summary there is evidence that the experience of hip fracture is traumatic and carer burden is an issue after hip fracture. Studies are of variable quality and do not include people with memory loss or take place in the early phase of recovery. This study therefore aims to gather evidence about patient and carer experience including where possible those with memory loss in the early phase of recovery in the hospital setting.

STUDY DESIGN

Aim

To explore patients who have had a hip fracture and their relative's/carer's experience of recovery during hospitalisation.

The research questions are:

What is the experience of older people who have suffered a fractured hip during the acute phase of recovery whilst in hospital?

What is the relative's/carer's experience of being alongside a person who has suffered a fractured hip during the acute phase of recovery whilst in hospital?

Methods

The theoretical perspective for this study will draw on the principles of hermeneutical phenomenology. Phenomenology is commonly used in health research to provide an understanding of the experience of a phenomenon (Mackey, 2005). The emphasis is on the world as lived by the person. Hermeneutical phenomenology allows exploration of how participants come to know and understand the world through their embodied experience within a wider historical and social context (Laverty, 2003; van Manen, 1990).

Two methods will be used in this study: semi-structured interviews and participant observation. Interviews are normally the method of choice in phenomenology as language is a key way of expressing experience. In addition we also chose participant observation as it provided an opportunity to sit alongside people who may find interviews challenging. Patients with capacity may choose to take part in one interview and/or one observation session. Patients without capacity may take part in one observation session if a personal consultee provides advice that the participant would not object to taking apart. Staff may choose to take part in the observation part of the study. Relatives/carers may choose to take part in one interview.

Interviews are a way of gathering information about individual's social world by listening and interpreting what people say about their experience whilst being aware of the meanings, beliefs and values that underlie their descriptions (Bryman, 2015). As well as gathering the views of individuals with a fractured hip, who have capacity to consent, we also plan to interview a relative/carer who actively participates in sharing the patient's injury experience on a practical and/or emotional level. Their experience of supporting a family member/friend with a fractured hip will help to situate patient's own experiences and vice versa. Although experiences will be treated independently,

concerns and challenges may be highlighted across the two groups. The main focus of the interviews will be around the experience of having a fractured hip or caring for a person who has a fractured hip. We will ask what having a hip fracture or caring for someone with a hip fracture is like. This will be followed up by prompts such as tell me more about? How did you feel about that? The interviews will normally take up to 60 minutes or may be broken up into several short sessions depending on the participant's degree of frailty. Patient interviews may take place on the ward due to issues around mobility. If this occurs due care and attention will be paid to patients' privacy and dignity. The relative/carer interviews will normally take place in a quiet room away from interruptions; an interview room is normally available. We will also offer participants the opportunity to carry out a telephone interview if they are unable to meet in the hospital environment. All interviews will be digitally audio-recorded, downloaded onto a password protected computer for analysis and transcribed verbatim.

In addition, this study includes participant observation to strengthen understanding of the experience of having a fractured hip and ensure that patients without capacity are included in the study. Participant observation will take the form of sitting alongside participants and experiencing the daily activities of ward life with them at various times of the day if appropriate. This will include informal chats with patients, as appropriate, about their experience. This technique allows the researcher to have longer and closer contact with patients in order to deepen understanding of the explicit and tacit aspects of their experience (Bryman, 2015). Close observation involves an approach that is similar to being a relative/visitor while retaining a hermeneutic alertness to situations that allows the researcher to constantly step back and reflect on their meanings (van Manen, 1990). Each observation session will normally take up to four hours according to the activities taking place on the ward and the patient's wishes. This was felt to be an appropriate length of time due to the frailty and aged nature of this group. Shorter periods of observation at different time points were considered however advice from staff and the trauma user group suggested this approach would be less disruptive for patients. The participant may stop the observation session or take a break and reschedule if they wish at another time. If preferred the observation period could be shorter and take place at several different time points. The researcher will be continually alert to cues that the patient wishes to be left on their own.

The main focus of the observations are the practical issues within the experience of having a hip fracture. According to (Merriam, 1998) this includes: physical situation, participants, activities and interactions, conversations, subtle factors (such as unplanned activities, nonverbal communication, for example expression and management of pain), and the researcher's own behaviour. For example a physiotherapist may come to help the participant to walk; the participant asks if she can come later after her pain killers have had time to work. This provides an opportunity for the researcher to inquire about her experience of pain since injury and how it has been managed. A patient with memory loss may appear to be agitated and a nurse suggests that she holds her handbag as this has a comforting effect and is what she does at home. This might create an opportunity to talk about the handbag and memories of its use that might be relevant to their current experience.

Core staff, such as their primary nurse or support worker, who take care of the patient will be invited to consent to take part in the observation period. This will provide them with the opportunity if they wish to make informal observations as part of the field notes after the period of observation. Staff may volunteer to consent and contribute but they are not the direct focus of this study and hence

are a convenience sample directly related to the participant observation with the patient. Written field notes using a paper notebook and pen will be taken during, as appropriate, and immediately after participant observation.

Sample

The setting will be two trauma wards in an NHS Foundation Trust with an average intake of 500 patients with hip fracture per year. The aim is to obtain a group that contains a range of age, ethnicity, sex, experiences and include people with memory loss. This will ensure a breadth of experiences, gender differences for instance can differ based on roles and responsibilities within the family and concerns about ability to return to normal household activities (Saletti-Cuesta et al., 2016). It is planned to recruit a purposive sample of: up to 40 patients or until saturation of themes, who have suffered a fractured hip, and up to 30 of their relative/carers or until saturation of themes, and up to 20 staff may choose to take part in the observation sessions. The sample size is based on the likelihood of saturation; normally 20-25 interviews are considered adequate (Charmaz, 2014; Marshall et al., 2013). An increased sample size was chosen to allow for interruptions, uncertain discharge plans, frailty of interviewees and inclusion of those with memory loss.

The inclusion criteria will be: patients who are 60 years or older with a fractured hip; relatives/carers who normally take care of/support a person who has suffered a fractured hip; and staff who care for the patient. The exclusion criteria will be patients with severe depression or delirium. Potential patient-participants will not be approached until at least the third day after surgery as they will not be fit enough to take part in research and clinical staff will guide the researcher in relation to their state of health. For participants with memory loss the Abbreviated Mental Test Score (AMTS undertaken clinically pre and post operatively) of less than 8 will be used to guide the researcher alongside advice from the clinical team.

Data collection

Clinical staff will initially identify patients and relatives/carers and will ask eligible participants if they are happy to be approached by a researcher. If so, the researcher will meet them face-to-face to explain and discuss the study. She will provide a copy of the Participant Information Sheet. A visit will be arranged normally 24 hours after contact to allow the potential participants to read the Participant Information Sheet and discuss with family/carers/friends or staff. The Participant Information Sheet outlines the focus of the study which is to understand the experience of recovery from hip fracture or experience of providing care/support for their relative/friend. The focus is therefore on the individual and the things that are important to them. The care they receive may be part of this experience. If they feel uncomfortable at any time the interview will be stopped and their needs met. The sheet also clearly identifies that they may withdraw from the study at any stage with no undue consequences. If the participant is happy to proceed, then, the participant will provide their written consent. Also, interested relatives or carers might contact the study team by telephone or email if they have seen the poster information that will be put up in the trauma setting. Relatives/carers may be anyone who has provided emotional or practical support to the patient who has suffered a hip fracture either before or during hospitalisation.

Staff will be informed through teaching sessions and individually if they are caring for a patient who has agreed to take part in a period of observation or whose personal consultee has advised that they

would not object to taking part. If they agree to consider the study they will be given a Participant Information Sheet and invited to take part in the study. If they volunteer to take part they will be asked to sign a consent form prior to the observation taking place. However, there will be staff from which it will not be possible to gain prior consent. If an interaction is noted in which a staff member takes part they will be asked to give their written consent to inclusion of the event in the study after the interaction has taken place. If they do not wish to consent the interaction will be excluded from the field notes. In addition, verbal permission to be in their space will be asked of the other patients in the room.

For patients with memory loss, Dewing (2008) identified a process of inclusionary consent with key elements: ensuring those who care for the person are involved; knowing the person, their normal response patterns and ability to make choices; finding creative ways of telling them about the study; regarding consent as continuous and ongoing; and providing support that includes the person in helping them move from one experience to another such as the researcher leaving the area. This process will be used alongside a personal consultee. Clinical staff will ask an eligible person who has a close relationship with the patient (personal consultee) if she/he is happy to be approached by a researcher regarding this study. If so, the researcher will explain and discuss the study, provide a copy of the Participant Information Sheet and will invite a personal consultee to advise her regarding whether the patient would object to taking part in an observation session. Clinical staff will decide based on their knowledge of the patient whether it is appropriate to undertake the observation session at any given time.

The participant with memory loss will be asked for their verbal or non-verbal agreement for the researcher to be there. In this study, like informed consent their agreement is defined as an ongoing process which is revisited and re-established on every occasion and may require renegotiations over time (Moore & Savage, 2002). Therefore, the researcher will remain alert to any changes in the participant's mood and discomfort following the principle of inclusionary consent to ensure the participant is comfortable at all times and recognising them as active persons that can communicate their wishes and agreement to participate or not in the research (Dewing, 2008). As Dewing (2008) suggests this might enable the person with memory loss to take part in the research in a meaningful way; feeling useful and participating may be of therapeutic benefit.

Ethical considerations

Ethical considerations are woven throughout this protocol for example ensuring that participants are able and have time to make an informed consent. For participants with memory loss, that they have a personal consultee and have an opportunity to take part in the study as far as they are able to contribute. All participants will be informed orally and by written information. Informed consent is taken in a written form. Each participant has the right to withdraw from the study at any time without providing a reason. Anonymity of participants, transient participants such as staff who might be part of the observation, people in the observation area such as other patients and visitors, will be maintained at all times. The study will comply with the Data Protection Act which requires data to be anonymised as soon as it is practical to do so. Participants will not be named on their interview transcripts. Care will be taken to remove any identifying information given in interviews. All documents will be stored securely and only accessible by study staff and authorised personnel. This

study has been reviewed and given a favourable ethical opinion by the National Research Ethics Service Committee and has Research and Development approval and sponsorship.

During data collection the researcher will be constantly vigilant for cues regarding patients' needs for comfort, respect and dignity and will stop the research, move away or obtain clinical help as required. A participant may feel upset if some aspects of their experience have been emotionally hard to manage, if this happens the researcher will stop the interview and provide support in the short term. Further support will be based on the participant's preferences, such as informing a nurse or if appropriate a visiting relative.

If during data collection unsafe practice is witnessed, this will be raised with a senior member of the ward team. The researcher will undertake responsibilities of disclosure within the principles outlined by the Nursing and Midwifery Council (NMC, 2015). If she encounters care that requires immediate action to ensure patient safety, she will take appropriate steps to do so. If patients or relatives/carers mention they want to make a complaint against a healthcare professional, the researcher will direct them to follow the complaint procedures as outlined on the hospital website. The website provides an email address to send complaints to, as well as further direction to the Patient Advice and Liaison Service. Their telephone number will be included on the patient information sheet.

The researcher will be separate from the clinical team but has a responsibility to feed into on-going staff development. The findings will be discussed with the trauma team in a sensitive way to allow for the team to share their views and feelings regarding caring for this group. Key senior clinical staff will be part of the advisory group. Learning will occur as part of ongoing practice development work supported by the research team and building on previous research activity.

Data analysis

The audio-digital recordings of the interviews will be transcribed verbatim after each interview. Field notes will be typed up after each period of observation. The process of analysis will be on-going throughout recruitment allowing researchers to build up a gradual picture of the experience of having a fractured hip. Reading and re-reading of the transcripts will help to familiarise the researcher with the data (van Manen, 1990).

Units of meaning will be identified from the words and phrases participants used, units with similar meanings will be gathered together into themes such as 'struggling to move' 'being in pain'. The process of analysis involves a constant moving back and forward within transcripts and across transcripts. Differences and similarities between the transcripts will be explored; how they were similar to, or different from the theme, and in relation to the findings as a whole drawing on the principles of the hermeneutic circle (Mackey, 2005). This idea is helpful in the iterative process of analysis when moving back and forth between different aspects and meanings within the participant's experience, all of which relate to one another (Smith et al., 2009). The analysis will develop what (van Manen, 1990) identifies as 'structures of experience' (p90). They capture important meanings across participants in relation to the research question, and represent some level of patterned response or meaning across a data set (Braun & Clarke, 2006)

Data from patients and relatives/carers will be analyzed separately but there will also be an awareness of the relationships between the data sets. Observation data will be treated in a similar manner. NVivo 10 (QSR) software will be used to assist with the management of the data. The process of analysis will be supported with critical insights from the advisory board and through discussion in the research team. The advisory board will include senior clinical staff, external researchers and patient/carer partners who will have the opportunity to discuss developing themes and assist with the implications for practice and dissemination of the study. In addition, through reflexivity the researcher will examine her own subjectivity within her fieldwork and throughout the process of analysis. Adopting this position requires the researcher to take into account her subjectivity and positionality (class, gender, ethnicity) and that of the researched and acknowledging the part played by such factors and her own understandings of the world (Bryman, 2015). The data collection and analysis will be supervised by a second researcher and there will be opportunities for debate and reflection throughout the process to ensure trustworthiness of data analysis.

Rigour

Trustworthiness is one of the primary criteria to ensure rigour and assess a qualitative study (Guba & Lincoln, 1994). This concept includes the identification of credibility, transferability, dependability and confirmability.

- Credibility is concerned with truth-value and whether the data reflects the participant's reality. In this study credibility will be demonstrated through engagement with the data, checking with participants to ensure understanding, offering them their transcripts to check, gathering data from a range of people and through two different methods - interviewing and participant observation.
- Transferability refers to the usefulness of the findings to other areas of practice. This will be demonstrated through identification of the sample, providing a detailed report and linking the findings to the current knowledge base. The advisory group will also help through involvement in the analysis and dissemination of the findings.
- Dependability and confirmability are concerned with making the research process explicit. Providing a clear audit trail of the decisions though ensuring that complete records are kept of all phases of the research process including: problem formulation; selection of participants; fieldwork notes; interview transcripts; and researcher's diary about her experiences, impressions, ideas and analysis throughout the research process (Bryman, 2015).

CONCLUSION

The strengths of this protocol is that patient and relative/carer experiences are collected in acute care whilst they are still in the early phase of recovery. Being able to include patients with memory loss through participant observation adds to the evidence as they are seldom included. Drawing on inclusionary consent for people with memory loss provides an ethical frame for including people with memory loss within a sample. Using two different sources of information may strengthen the data as different aspects of experience may be illuminated. Data collection in an acute setting may allow the researcher to use her own thoughts and feelings as points of reflection through being alongside participants within the research context. A further strength is having two researchers

involved in the study throughout the research process and analysis creating opportunities for reflection and debate and ensuring trustworthiness of the study.

Limitations

The acute environment can be a difficult context for research as participants may have a range of symptoms and interventions as a result of traumatic injury. This may limit the time available and depth of interviews obtained. An ability to provide adequate privacy may also be limited in a busy ward environment. Obtaining enough participants with memory loss may be problematic if suitable personal consultees are not readily available and a professional consultee could have been considered. Undertaking data collection at a range of time points during the patients' hospitalisation may yield a more in-depth understanding of the participants experience over time. Inclusion of staff experiences of caring for this group of patients may have provided a more rounded sense of the environment of care.

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